Workgroup F: Chronic Care Rationale for Recommendations As presented to the Governor's Task Force on October 11, 2004

Introduction

Workgroup F was charged with ensuring that long term care policy "acts to support, implement, and sustain prevention activities through community health principles, caregiver support, injury control, chronic care management and palliative care programs that enhance quality of life, provide person-centered outcomes, and prevent unnecessary hospitalizations or institutionalization."

The group voted to adopt this revised principle. The key differences from the original principle include:

- 1. The adoption of the term "chronic care" as opposed to "chronic disease." This change reflects a pointed focus on the person and all of their needs rather than a focus on a medical diagnosis. It also prevents focusing on one disease and ignoring co-morbidity.
- 2. The group chose to add the words "implement and sustain" to emphasize the potential power and lasting impact of the adoption of this principle.
- 3. The group expanded the outcomes listed in the principle to include "enhance the quality of life, provide person-centered outcomes, and prevent unnecessary hospitalizations or institutionalization."

Given this revised principle, our subcommittee focused on wellness, injury prevention and chronic care management as critical elements that impact the delivery and cost of long term care.

According to the Centers for Disease Control and Prevention website, 33.7 million Americans of all ages have limitations in their activities due to a chronic condition. This equates to 12.1% of the population. A full 6.7% of children have a chronic disability that affects their activities. Disability related to chronic condition disproportionately affects people of color and people near or below the poverty line.

People with disabilities of all ages, races, ethnicities, and economic backgrounds, and their caregivers, need to understand and utilize community-based resources including respite and prevention options. Caregiver support is an essential element of any long term system. Nationally, one in four families is providing caregiving, and more than 80% of long term care is delivered by informal caregivers.

Currently, there is not a coordinated method to encourage community health and wellness, implement injury control programs, or assist individuals/caregivers with chronic long term care issues. Creating new incentives is one way to expand utilization and development of resources to manage costly and debilitating chronic health conditions. Taking advantage of some of the energy being created by the Healthy Aging Initiative of OSA and the State's Public Health Department and the expertise and interest which currently exists is a way to start coordinating the community health and wellness portion of this charge.

Recommendations from Workgroup F are organized according to three focal points: 1) Community Health; 2) Family and Caregiver Support; and 3) Chronic Care Management and Injury Control. The matrix of recommendations lays out a framework for creating needed incentives and changes that will enhance the long term care structure for Michigan residents.

Rationale for Matrix 1: Community Health

Community Model & Points of Prevention: Prevention of injury, disease and excess disability occurs at three points in time. Primary prevention is aimed at eliminating the cause of disease or disability, such as through pre-natal care, automobile safety, or weight reduction. Secondary prevention is initiated at the onset of disease or disability, and requires triage, ongoing effective treatment, and follow-up, in order to promote effective healing and recovery. Tertiary prevention is concerned with the management of residual disability, of progressive or chronic disease, and of age-related decline, with the purpose of maximizing quality of life, and eliminating or reducing complications.

Long-term Care is a Multigenerational Issue: Concerns about the increasing proportion of older adults in American society are driving awareness of the need to reform LTC in order to improve quality and contain costs. However, in addition to the elderly, others are seriously affected by the design of both the acute care and long-term care system, in particular, people with a disability of any age and those with chronic and progressive illness at any age. Further, many community interventions aimed at prevention, such as increasing exercise, can directly benefit all age groups. Reductions in disability and disease occurrence and impact, along with efforts to ease the work of family or volunteer caregivers, can indirectly improve the health and well-being of other family members.

Community Perspective on Chronic Care: A community perspective focuses not only on costs and benefits to a designated "consumer", but also evaluates interventions for their positive effects on family caregivers, workers, providers, and the community at large. Further, a community-based approach mandates greater interaction across service "silos", and governmental branches (e.g., transportation, driver safety, and mobility issues). The goal is to promote among all members of society, a "sense of coherence" (Antonovsky) in which there are structures in place to prevent as well as mitigate the many personal tragedies caused by disease, accident, and age-related decline.

Rationale for Matrix 2: Family and Volunteer Caregiver Support

The vast majority—70-80%--of LTC is provided by family members (AARP, 2001; Tennstedt, 1999). The most likely caregiver of an older adult is the spouse, who is typically of similar age. Next in line to assume primary care of an older adult is an adult daughter. Other family members also provide care and support. Most caregivers live with or near the care recipient. Some caregivers are "long-distance" caregivers, residing more than an hour away from the care recipient. Family caregivers provide direct services themselves, supervise formal services, and assist care recipients in acquiring health services.

Family caregivers report many rewarding aspects of caregiving, primarily, knowing that the loved one is receiving good care (NAC, 1998). Despite rewards, family caregiving of the elderly does not come without costs or risks to the caregiver. Decades of research indicate an associated risk of psychological strain and depression (Barer & Johnson, 1990; Schulz & Beach, 1999; Schulz & Martire, 2004; Schulz, Visintainer, & Williamson, 1990). Prospective studies have linked caregiving with increased mortality (Schulz & Beach, 1999). Many caregivers reduce work hours, and may leave the workforce entirely, putting their own retirement plans in jeopardy. Little is known about the short and long-term effects of caregiving on other family members such as the spouse or children (Hunt, 2003).

The period of caregiving may be lengthy, particularly for those taking care of someone with a dementing illnesses. Many caregivers reach a point of emotional and physical exhaustion, or caregiver "burnout" without even realizing it (Almberg, Grafstrom, & Winblad, 1997; Smith, 1997).

Family caregivers often neglect to take care of themselves, since they may view the well-being of the care recipient as the priority and have little time or energy left over for their own health care. Family caregivers often do not think of themselves as "caregivers", but instead assume that caregiving is "what someone does" as part of one's relationship and commitment to spouses, parents, children, or other loved ones (Hoffman, 2002). Caregivers may have difficulty juggling multiple roles and responsibilities such as work and child care (Brody, 1981), and suffer anxiety, frustration and guilt.

Workgroup F proposes that "wrap-around protocols" be developed and implemented that address both the consumer and the caregiver support needs, in order to prevent harm to both the consumer and the caregivers. There are several "best practices" and models on caregiver support systems (e.g., the REACH multi-site studies; Montgomery's intervention model) featuring components of information and referral; use of formal services; teaching problem-solving approaches; support groups and individual counseling; respite; stress and behavior management; and self-care.

Caregivers report difficulty in accessing needed information; care options are expensive and differences among services and residential settings may be confusing; many are unaware of what services are available or of how to find out about them, or how to pay for them. Many report difficulties in "navigating the health care system." Despite the longitudinal nature of some conditions, such as dementia, caregivers often are not prepared for the eventual decline of the care recipient and the incumbent care requirements. Caregivers often consider moving care recipients out of their homes into congregate settings as a "last resort," or when they feel they "have no choice"(Liken, 2001; Newman, Struyk, Wright, & Rice, 1990; Reinhardy & Kane, 2003; Young, 1998).

Supporting caregivers means helping the care recipient since the first and foremost concern of most caregivers is quality care for the care recipient. Since long term care is expensive and quality of care is a concern, approaches that sustain personal and family

energy for caregiving are needed. Able and informed caregivers are needed to advocate for care recipients unable to do so for themselves throughout the health care system.

Matrix 3: Chronic Care Management and Injury Control

There need to be good connections between acute care and long term care systems in order to promote cost savings and quality care (Virginia Dize, Associate Director of the National Association of State Units on Aging—Michigan Society of Gerontology presentation, 9/29/04). States which have broad-based single-point-of entry systems are most likely to contain long term care costs (Robert Mollica, National Academy for State Health Policy, Michigan Society of Gerontology presentation, 9/29/04). Workgroup A of the Governor's Task Force has proposed a single point of entry system for long term care which could be one platform for the coordination of acute and long term care. Other states have begun to use models which Michigan can analyze for best practices and adaptation based on a process that includes the major stakeholders who could make this coordination a reality.

There are unique aspects of care of the elderly and people with disabilities that differ from able-bodied adults. The lack of health care providers specifically trained in principles of geriatric care has been noted for virtually all levels of providers, including direct care workers, nurses and physicians (IOM, 2001). For example, medication management for the elderly is very different due to the risk of side effects and toxicity from polypharmacy. Unfortunately, due to the lack of specialized training in geriatrics or disabilities, older adults and people with disabilities are often treated inappropriately. Medication management is a frequent need of both populations.

Few provider curriculums fully instruct their students in issues relevant to health care financing and alternatives among long term care settings for the elderly or disabled. Even fewer provide content and practica in rehabilitative medicine, assistive technology, and mobility devices. Despite the ability of assistive devices and technology to reduce dependence among the disabled, they are grossly under-utilized, due in part to costs or lack of awareness (DRA, 2001).

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(revised)

Principle: Acts to support, implement, and sustain prevention activities through community health principles, caregiver support, injury control, chronic care management and palliative care programs that enhance the quality of life, provide person-centered outcomes, and prevent unnecessary hospitalizations or institutionalization.

General Area: Community Health

Goal: Develop and provide incentives for local collaboration, including public health, to actively promote healthy aging through preventive and chronic care for all age groups.

Strategy 1: Develop a DCH-led workgroup comprised of legislators, MSA, OSA, FIA stakeholders/ consumers, and others to oversee the collaborative process involving local public health entities engaged in prevention/chronic care. Under the direction of the DCH-led workgroup, local entities will:

- 1. Convene a broad-based coalition of aging, disability and other organizations.
- 2. Review community resources and needs (including prevention, chronic care and caregiver supports).
- 3. Identify existing local, culturally competent strategies to address prevention, chronic care needs and substance abuse.
- 4. Develop and support programs to address prevention, chronic care, and caregiver supports.

Operational Steps:

A DCH-led workgroup:

- 1. Defines criteria for local entity participation
- 2. Defines incentives for participation.
- 3. Defines "healthy communities" (inclusive of prevention and chronic care).
- 4. Involves stakeholders in planning, contract development, review, and selection.
- 5. Establishes the charge to local entities, with time frames.
- 6. Implements prevention and chronic care activities locally and statewide.
- 7. Monitor and evaluate outcomes.

Success Measure Examples:

- 1. Needs assessments are conducted, completed, and reviewed.
- 2. Gap analysis report is created based on needs assessment.
- 3. Local and statewide groups complete plans to address local health and wellness gaps.
- 4. Executed contracts in place with local existing entities, which are broad-based (including the aging and disability community) to address gaps.

5. Completed workgroup report evaluating progress, outcomes, and identifying next steps.

Potential Barriers to Strategies:

- 1. People with chronic conditions are often ignored in prevention efforts.
- 2. Turfism.
- 3. Funding.
- 4. Overlapping programs and gaps in programs.
- 5. Lack of expertise and demonstrated evidence to implement culturally competent strategies.
- 6. The current system rewards a lack of prevention because money is focused on acute care.

Ways to Address Potential Barriers:

- 1. Reduce turfism by requiring local collaborative groups.
- 2. Look at state-level programs and identify gaps and overlaps.
- 3. Collaborative efforts can save money through pooling of resources.
- 4. Create budget-neutral incentives to drive process.
- 5. Outreach to underrepresented areas (minorities, PWDs) to improve cultural competence.
- 6. Involve local government, private sector, non-profits, and faith-based organizations.
- 7. Tap into culturally competent expertise from ethnic groups themselves and professional sources such as, but not limited to RWJ, SAMHSA, HRSA, CHCS, and universities.

Suggested Time Frame:

MDCH-led workgroup convenes within two months of final report

MDCH-led workgroup issues strategies/ guidelines within 6 months of convening

General Area: Family and Caregiver Support

Goal: Develop and implement legislative/ administrative initiatives to provide financial and other support to caregivers. Natural supports are sustained.

Strategy 1: Promote the use of culturally competent training of caregivers on injury prevention, rights and benefits, and person-centered planning.

Operational Steps:

- 1. Research best practices in caregiver training and support programs, including private sector initiatives.
- 2. Create a plan to implement select "best" caregiver training and support best practices.

Success Measure Examples:

1. Every local region has a program in place to train caregivers that is culturally competent to the needs and culture of the informal caregiver.

Strategy 2: Develop wrap-around protocols for caregiver/consumer support needs.

Operational Steps:

- 1. Add more extensive caregiver needs assessment to the Medicaid funded screenings (Home Help, MI Choice).
- 2. Address caregiver needs in care plans.
- 3. Develop a crisis and back up support system for caregivers.

Success Measure Examples:

- 1. Consumer supports are increased and better utilized.
- 2. Caregiver needs screening incorporated into Medicaid-funded screening instruments.
- 3. Upon retrospective review, address caregiver needs.

Strategy 3: Develop a public health caregiver support model.

Operational Steps:

- 1. Create a registry of family caregivers for information and connection to informal supports, networking, and resources.
- 2. Maintain or increase effective existing programs.

Success Measure Examples:

1. Registries completed with processes in place for ongoing updates.

Strategy 4: Create initiatives and incentives to support caregivers.

Operational Steps:

- 1. Provide incentives to alleviate care/ respite costs.
- 2. Provide health care coverage options for caregivers.
- 3. Create employer incentives for offering flexible policies for employee caregivers.

Success Measure Examples:

1. Legislative and administrative initiatives are in place and used.

Potential Barriers to Strategies:

- 1. Respite is underutilized and costly.
- 2. People do not self-identify as caregivers.
- 3. There are not enough culturally appropriate respite options.
- 4. Legislative/Administrative initiatives are confusing with varying stipulations (age, disability, etc).
- 5. There is inequity in funding based on age.
- 6. The current system rewards a lack of prevention because money is focused on acute care.

Ways to Address Potential Barriers:

- 1. Publicize definition of caregiver so that people can self identify as a caregiver.
- 2. Normalize the use of supports through a public relations campaign.
- 3. Push for "Money Follows the Person" which would address the needs and desires of consumers and the current funding inequities.

Suggested Time Frames:

Marketing campaign initiated within 12 months after submission of Task Force final report.

General Area: Chronic Care Management and Injury Control

Goal: Increase the use of "best" chronic care models.

Strategy 1: Identify and promote the use of elements of established models for chronic care management and coordination (e.g., Wagner or ACOVE model).

Operational Steps:

- 1. Select desired chronic care model(s).
- 2. Determine how model will be applied and utilized.
- 3. Issue guidelines for model's use and implement an award program to promote use.
- 4. Evaluate protocols to ensure consistency with selected chronic care model.

Success Measure Examples:

- 1. Increase in the number of providers trained and adopting the models.
- **Strategy 2:** Create incentives for implementing culturally competent chronic care models and protocols.

Operational Steps:

1. Identify and implement options to incentivize increased/expanded educational programs on gerontology, disability, and chronic care.

Success Measure Examples:

- 1. Medical schools and nursing/ancillary healthcare programs expand their curricula to include chronic care.
- 2. Increase numbers of students graduating schools with established chronic care curricula/programs.
- **Strategy 3:** Develop and implement chronic care protocols, including, but not limited to:
 - 1) medication usage
 - 2) identifying abuse and neglect, caregiver burnout / frustration
 - 3) caregiver safety and health.

Operational Steps:

- 1. Promote the use of effective screening tools to identify individuals at increased risk in 1 or more of the following domains: cognitive, physical, mood, environmental, social/spiritual.
- 2. Establish and require standards for chronic care coordination in the Medicaid long-term and acute care system (acute/long-term community resources coordination); care coordination should address each of the domains mentioned above as appropriate and specifically adopt established guidelines for:
 - a. Reviewing and addressing medication usage.
 - b. Screening for potential abuse and neglect.
 - c. Professional and peer outreach programs for caregivers.

Success Measure Examples:

1. Increased number of providers using screens and protocol-driven interventions.

Strategy 4: Promote the use of Assistive Technology (AT) for consumers and direct care workers/caregivers as a prevention tool.

Operational Steps:

1. Ensure access to AT services are part of person-centered service and supports plan.

Success Measure Examples:

1. Increased use of assistive technology as reflected in the person-centered plan.

Potential Barriers to the Strategies:

- 1. Many chronic care guidelines are not evidence-based.
- 2. Lack of time and resources
- 3. Lack of curriculum in schools on aging, disabilities and chronic care

Ways to Address Potential Barriers:

- 1. Ensure that selected model and guidelines are evidence-based.
- 2. Allow multiple opportunities for program referral (including self/family identification.
- 3. Use tools in community (not just primary care office).
- 4. Establish a "case-mix" type payment structure to allow more time spent with individuals who are at high risk or have more needs.
- 5. Reward results.

6. Expand educational options covering aging, disabilities, and chronic care.

Suggested Time Frame:

Implement operational steps within 1 to 2 years.

Matrix of Recommendations

institutionalization.						
Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame	
Community Health Develop and provide incentives for local collaboratives, including public health, to actively promote healthy aging for all age groups (including chronic care).	Develop a DCH-led workgroup comprised of legislators, MSA, OSA, stakeholders/ consumers, and others to oversee the collaborative process involving local public health entities in prevention/chronic care. Local entities will: Review community needs and resources (including chronic care and caregiver supports); Identify existing local,	DCH-led workgroup: Defines criteria for becoming a local entity; Defines incentives for local entities; Establishes a charge to local entities, with time frames; Involves stakeholders in contract development, review, and selection; Defines "healthy	 Executed contracts in place with local existing entities, which are broad-based (including the aging and disability community); Needs assessments are reviewed/ completed; DCH-led workgroup oversees and evaluates progress; Gap analysis report is created by local groups; 	 Barriers: People with chronic conditions are often ignored in prevention efforts Turfism Funding Overlapping programs and gaps in programs Lack of expertise in culturally competent strategies The current system rewards a lack of 	MDCH-led workgroup convenes within two months of approval by the task force MDCH-led workgroup issues strategies/ guidelines within 6 months of convening	
	, ,	and selection;	created by local	The current system		

Matrix of Recommendations

Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame
	chronic care needs and substance abuse; and	(inclusive of chronic care)	plans to address local needs.	money is focused on acute care	
	Convene a broad- based coalition of			Addressing Barriers:	
	aging, disability and other organizations.			 Reduce turfism by requiring local collaborative groups 	
				 Look at state-level programs and identify gaps and overlaps 	
				 Collaborative efforts can save money through pooling of resources 	
				 Use budget-neutral incentives to drive process 	
				 Outreach to underrepresented areas (minorities, people with 	

Matrix of Recommendations

Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame
				disabilities) to improve cultural competence	
				 Involve local government, private sector, non-profits, and faith-based organizations 	
				 Tap into culturally competent expertise (RWJ, SAMHSA, HRSA, CHCS, universities) 	

Matrix of Recommendations

mondification.	Stitutionalization.							
Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame			
Unpaid Caregiver Support								
Develop and implement legislative/ administrative initiatives to provide financial and other support to caregivers Unpaid caregivers are supported.	An OSA/CIL/DCH-led workgroup that includes nonprofits, universities, Area Agencies on Aging, and 50% consumers/ caregivers including people with disabilities and seniors: 1. Develops a process for training caregivers on injury prevention, rights, and benefits (trainers are culturally competent); 2. Creates a voluntary registry of caregivers for information and connection to informal supports, networking, and resources.	 Tax deductions for care/respite costs Subsidies Health care coverage options Employer incentives for offering flexible policies for employee caregivers Maintain or increase effective existing programs Support private sector initiatives Research best practices caregiver support programs Plan to implement/incentivize chosen best practices 	 Every county has a program in place to train caregivers Legislative and administrative initiatives are in place and used Consumer supports are increased and better utilized 	 Respite is underutilized and costly. People do not self-identify as caregivers. There are not enough culturally appropriate respite options. Legislative/Administrative initiatives are confusing with varying stipulations (age, disability, etc). There is inequity in funding based on age. Addressing Barriers: Publicize definition of 	The workgroup convenes within 2 months of approval by the task force. A process for financing and training caregivers is established within 6 months. A process for establishing a registry is established within 3 months of convening the group. The registry is created within 6 months. The wrap-around protocols are			

Matrix of Recommendations

Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame
	The primary focus of this registry is unpaid caregivers; 3. Develops wrap-around protocols for caregiver/consumer support needs; and 4. Develops a public health caregiver support model.	 Add more extensive caregiver needs assessment to the Medicaid funded screenings (Home Help, MI Choice) Address caregiver needs in care plans Develop a crisis and back up support system for caregivers 		caregiver so that people can self identify as a caregiver. Normalize the use of supports through a public relations campaign. Push for Money Follows the person which would address the needs and desires of consumers and the current funding inequities. Use the SPE to address caregiver needs in an ordered way.	developed within 6 months of convening. The Public Health model is developed within 8-10months.

Matrix of Recommendations

Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame		
Chronic Care Management and Injury Control							
Identify and promote use of "best" chronic care models	A Public Health-led group that includes MSA, Mental Health, Substance Abuse, OSA, Consumers/ Stakeholders, Doctors, and Universities: Identifies and promote the use of elements of established models for chronic care management for people of all ages and coordination (e.g., Wagner or ACOVE model); Creates incentives for implementing culturally competent chronic care models and protocols.	 Select desired chronic care model. Determine how models will be applied and utilized. Pilot the model in 3 locations. Issue guidelines for model's use and implement an award program to promote use. Evaluate protocols to ensure consistency with selected chronic care model. Promote the use of effective screening tools to identify individuals at increased risk in 1 or 	 Increase in the number of providers trained and adopting the models. Increased number of providers using screens and interventions. Schools expand their curriculums. Increased numbers of students graduating from programs. Increase in money to expanded programs. Increased use of assistive technology as reflected in the personcentered plan. 	Most guidelines are not evidence-based. Lack of time and resources Lack of curriculum in schools on aging and disabilities and chronic care The current system rewards a lack of prevention because money is focused on acute care. Addressing Barriers: Ensure that selected model and	The workgroup convenes within 2 months of task force approval to address the needs of seniors, people with disabilities, and children. The pilot sites are chosen within 12 months. The group identifies, incentivizes, and promotes elements of models within 6 months of convening. Models are		

Matrix of Recommendations

Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame
Goal	Develops and implements protocols, including: o medication usage o identifying abuse and neglect, caregiver burnout / frustration o caregiver safety and health. A subcommittee plans to increase use of	more of the following domains: cognitive, physical, mood, environmental, social/spiritual. Establish and require standards for chronic care coordination in the Medicaid long-term and acute care system (acute/long-term community resources coordination). Care coordination should address each of the domains mentioned above as appropriate.	Success Measures	guideline have an established basis; Allow multiple opportunities for program referral (including self/family identification; Use tools in community (not just primary care office); Establish a "case-mix" type payment structure to allow more time spent with individuals who are at high risk or have more	implemented within 12 months of convening. The subcommittees to address assistive technology and university programming are convened within 2 months of task force approval with a plan 8 months after convening.
	Assistive Technology for consumers and direct care workers/ caregivers as a part of the protocol.	Identify and implement options to incentivize increased/expanded		needs; Reward results; and	
•	A subcommittee plans	educational programs on gerontology,		 Expand 	

Matrix of Recommendations

Goal	Strategies	Operational Steps	Success Measures	Barriers/Address Barriers	Time Frame
	to incentivize university programs in gerontology, disabilities, chronic and palliative care.	disability, and chronic care. Promote the use of assistive technology.		educational options covering aging, disabilities, and chronic care.	

Workgroup F has rewritten its originally assigned Visions and Values Statement/Principle and is recommending adoption by the Task Force of the altered Statement.

Original Principle: Actively supports and promotes community health, caregiver support, injury control and chronic disease prevention and management programs that reduce the need for long term services.